

An equality and human rights vision for care and support

Baroness Jane Campbell, Commissioner, Equality and Human Rights Commission

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Speaking at the launch of the Care and Support debate in May, I called for all stakeholders to come together to debate how we can create a support system 'where people's human rights are enshrined and everyone's life chances are equally valued and supported'.

So in what ways might care and support be different and what would such a system look like if we went down this route?

From freedom from, to freedom to

Our approach to care today is largely about ensuring **freedom from** the worst excesses of neglect, hunger, abuse, isolation and physical and mental pressures. Despite pockets of good practice, it is little more than a safety net.

To achieve the Equality and Human Rights Commission's vision, care and support tomorrow must be about offering individuals and families the **freedom to** lead rich, rewarding and valued lives.

Getting to this point demands first that we redefine the 'problem' we believe ourselves to be dealing with. Rather than how to meet 'care needs', we should ask how can care and support promote equality and human rights. Rather than ponder 'how to deal with growing dependency' we instead must ask: how can we support participation and well-being for individuals and families in ways which have clear social and economic benefits to society as a whole as we go through profound social change in the coming decades?

Equality and human rights – what are we talking about?

We all need to enjoy particular freedoms and opportunities to flourish as human beings. The Equalities Review, published in 2007, sought to identify what these most important freedoms and opportunities are. This set out the core aspects of what people need to realise their human rights and participate as equal citizens:

- **Longevity**, including avoiding premature mortality.
- **Physical security**, including freedom from violence and physical and sexual abuse.

- **Health**, including both well-being and access to high quality healthcare.
- **Education**, including both being able to be creative, to acquire skills and qualifications and having access to training and life-long learning.
- **Standard of living**, including being able to live with independence and security; and covering nutrition, clothing, housing, warmth, utilities, social services and transport.
- **Productive and valued activities**, such as access to employment, a positive experience in the workplace, work/life balance, and being able to care for others.
- **Individual, family and social life**, including self-development, having independence and equality in relationships and marriage.
- **Participation, influence and voice**, including participation in decision-making and democratic life.
- **Identity, expression and self-respect**, including freedom of belief and religion.
- **Legal security**, including equality and non-discrimination before the law and equal treatment within the criminal justice system.

If care and support has a role, then surely it is in assisting those who require particular support due to their condition or disability and their families to access these freedoms?

From theory to practice – what difference would it make?

If we accept these freedoms are the outcomes we want from a reformed support system, what might it mean for the way eligibility is assessed and services are used and delivered, and for the way we measure success?

In allocating resources, it is right that we continue to target resources at those in greatest need. Eligibility for support would be based on an assessment of the current or potential risk to both individuals and those associated with them of losing any or all of the freedoms listed above if support is not provided.

This necessarily means a proactive and preventive approach is required, in line with the positive obligations public authorities already have to promote and protect human rights.

So for example, in a number of the recent disturbing cases of men with learning disabilities being targeted, tortured and murdered, such as Steven Hoskin and Brent Martin, the attackers had previously engaged in a lengthy period of 'grooming'. They exploited the vulnerable situation

in which these men led their lives, isolated and largely unsupported, by becoming their 'friends'. As a society we failed to protect their right to physical security. In doing so we also failed to protect their wider freedom to live independently. A system based on promoting equality and human rights would identify and respond to the risks which lead people with learning disabilities to be targeted, recognising them as a trigger for support to be provided.

This approach would also change the way practitioners consider families. If we value family and private life as a core freedom, different decisions about caring in families might be made. We would ask 'at what point does relying on unpaid care begin to subvert valuable family relationships, creating intolerable pressures, and breaching freedoms for all concerned?' I know that if my PAs go off sick and I have to rely on my husband for support the main service we very quickly require is Relate counselling not a carers' support group!

Currently, care and support does not optimise employment opportunities, for disabled people, for people wanting to work into later life and for unpaid carers. In fact, the need for support is too often a trigger for the individual or a family member to leave paid employment, bringing avoidable hardship. Families should be eligible for support which optimises their collective opportunities for paid employment and which mitigates the risk of poverty.

Tackling these issues requires a sea-change in both when and how people access or receive support. Rather than managing dependency or crisis, the accent shifts to helping individuals and families mitigate risks and build capability to stay healthy, safe, develop skills, hold down a job or raise a family.

So for example, greater support through independent advocacy would help people with learning disabilities make transitions into appropriate work or make better decisions about the people they befriend. Local services working together, including social workers and neighbourhood police, would help older people feel more secure to engage with their community. More support for paid care could strengthen family life through improving the quality of family relationships, and allow carers access to a life outside their caring responsibilities.

An equality and human rights approach to care and support demands that we fashion a system which optimises a whole range of opportunities which are currently denied people who are in relationships of informal care and support or who need or use public services. Opportunities, for example, like placing greater control in the hands of individuals through

'portability' – allowing them to move their care package from one area to another to take up employment opportunities, or to be with faraway family or friends who might in turn become part of the circle of informal support which must complement public services if we are to make our ambitions a reality.

An equality and human rights approach would finally free us from the long shadow of the Poor Law.

If we focus on these freedoms as outcomes for all – whatever their disability or support need, and including families – we would have a wider vision of care and support and a firmer basis for offering genuine choice, control and personalisation. Both in the way we plan support, and in the way control is given to individuals through self-directed support, the scope of options to enable individuals to satisfy their needs can be opened up. This might encompass anything from home care as we know it through to the story of the couple who used their direct payment to buy a season ticket for the husband's football team, satisfying his desire to stay participating in the life of his community and pursue his passions, and her desire to have an occasional break and pursue her own interests.

How do we get buy in for this approach?

Perhaps the most beneficial aspect of an approach based on equality and human rights is that it is *universal* – we all anticipate these rights and freedoms – whilst still maintaining the principle of allocating the most resources to those in greatest need. Intuitively, this seems fair to people.

The second benefit is that the framework of outcomes gives us a way of assessing not just the costs of providing care and support, but the benefits. It points us to the 'opportunity costs' involved in not getting the right system. This will help us to make more rounded decisions both about the way we organise and deliver services, and how we think about spending on them. For example, based on Derek Wanless's projections, we may believe publicly funded support is an unaffordable option and instead focus more on sustaining family care-giving. Yet thinking about outcomes for all, we would question whether the projected 3 million extra unpaid carers outside the workforce is economically sustainable, and what's more socially sustainable, given its impact on women.

The framework of outcomes allows us to think through decisions about the future of care and support relative to their broader impacts, and in doing so build arguments for reform and investment in care and support

which engage the public, policy makers and those in charge of the country's purse strings alike.

What does the Equality and Human Rights Commission plan to do?

The Commission will play a full part in this debate. We are busy talking to stakeholders about their equality and human rights vision for care and support, including government departments and politicians. Later in the year we will publish a report setting out our ideas and proposals which we know will give substantive added value to this field of reform.

We believe an approach based on equality and human rights – the core freedoms we want for each human being – could provide the best way to modernise care and support. A better use of the resources we currently have at our disposal, for individuals, family and the country in meeting the challenges ahead. A better way to allocate those resources fairly. And a better way to ensure this agenda is genuinely recognised, as it should be, as being for everyone.

Please note: The views expressed by the author may not necessarily reflect the views or policies of the Department of Health.